

# Parent-to-Parent Support

### Meet the family:

Mom: Candace, hearing  
Dad: Ron, hearing  
Children: Luke, 9, deaf, profound  
Morgan, 5, hearing  
Communication Method:  
Sign, Cue, and Voice  
Newborn Screening:  
None available  
Age at Diagnosis: 8 months  
Uses hearing aid+cochlear

### Dear Parent:

Hearing loss was not the first or last diagnosis for our family. Our son Luke was our first-born. We were thrilled to be new parents, and we looked forward to sharing music, laughter, and being an active family. When Luke wasn't rolling over at four months, we knew something was wrong. When he still wasn't at six months, we were told that he had cerebral palsy on one side of his body. But they also warned us he might have many other challenges, including hearing loss.

So, we packed off to all sorts of medical professionals to cross off each on the long list of possible problems. To our relief, most of the issues never appeared. However, at eight months, we learned he was profoundly deaf. And, we grieved the loss of sharing music, listening to his little voice, and watching his body develop like other children. I thought I would never stop crying.

With time, we moved into taking action. This felt good. Our family learned sign language. Luke was fitted with hearing aids. And, we received incredible support from our local school district, professionals, family and friends. As difficult as this journey has been, I have considered these relationships to be life changing and powerful.

When Luke was almost four, he had cochlear implant surgery. This was a difficult decision for us but I would do it again. Only this time, I would have done it when he was younger. This boy, who could only feel a train go by and tried so hard to please the audiologists by pretending to hear sounds he couldn't, could hear speech. We cried again, but for different reasons. Soon, we would share our music, hear the sound of his developing voice, and his body would conquer many of the challenges of cerebral palsy.

Today, Luke is going into 4th grade. He also has ADHD. He is a child who signs, who is starting to use cued speech (a visual reinforcement system to spoken English), and who uses his voice. Not everyone can understand his speech, and he doesn't hear perfectly. He would far prefer to sign with someone, but he has many "tools" of communication to choose from. We hoped he would have a wide community to support him: a signing community, a cueing community and a hearing community. I rejoice when I hear and see him argue, laugh, chase, or share sweet moments with his younger sister, whatever communication method they choose at that moment.

My advice to you, a new parent just starting on this path and just beginning to understand your child and his or her needs, is: be kind to yourself. Allow yourself the time to be angry or disappointed. But also be reassured that your child will show you what he or she needs. Keep your mind open to what those needs are, and how to support them. Surround yourself with adults who have hearing loss, families who have children with hearing loss, and lots of good information about choices. Most of all, love that child. There are a lot of us here to support you along the way.

With best wishes for your future,

**Candace**

7.05

*For information about how to connect with a family like this, please contact the Family Support Connection at 1-866-DHOH-KID, or 651-265-2435 in the Twin Cities. Or, you can email [fsc@lifetrackresources.org](mailto:fsc@lifetrackresources.org).*